

**DEATH BEFORE LIFE: AN ANALYSIS OF EMERGING ADULTS' KNOWLEDGE
AND ATTITUDES REGARDING END-OF-LIFE DECISION MAKING**

by

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This study sought to address the significant paucity in the medical decision making literature regarding the knowledge and attitudes of emerging adults toward advance care planning. Using a mostly qualitative approach, we attempted to document several dimensions of preferences and perspectives within a population well known for risk-taking behaviors, which may result in death, serious injury, and states of decisional incapacitation. Fifty-six undergraduates from two Pittsburgh universities took part in six focus group interviews, held between February-April 2007. Using a semi-structured focus group guide, participants were led through discussions on hypothetical end-of-life care scenarios, eliciting their views on Living Wills, Health Care Proxies, preferences for surrogates and their behaviors, and for life-sustaining treatment. Content analysis revealed inter-subject variability and intra-subject inconsistency among participants within all domains analyzed. Fifty-six percent of our sample displayed correct knowledge of advance directives, while only 10% understood that they offer proxy designation. Themes related to age-mediated invincibility, decreased risk perception, and an inexperience with morbidity and mortality relative to their elders emerged from the data. The findings of our study underscore the need for a thorough, quantitative effort to examine this volatile population's familiarity and attitudes regarding decisional incapacitation and the legal provisions in place to ensure autonomous and/or shared decision making. Additionally, we review the psychosocial literature related to advance care planning and apply it to this population, suggesting that current legal

statutes may be inappropriate for this age group, given their ongoing individuation and identity development.

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PREFACE

I would be remiss to submit this work to close a chapter of my life, without acknowledging those who have guided me in the process. This project, whose roots are grounded in my father's struggle with brain cancer, has taken the better part of four years to complete, undergoing extensive and continuous refinement. In my freshman year, Rhonda Gay Hartman, JD, PhD, proposed that I reflect upon the implications of usurped autonomy through psychiatric manipulation and sedation during the terminal stage of brain cancer and other such cognitively degrading illnesses. From this experience, I realized that severe death anxiety masks itself as youthful invincibility, and influences many of my peers' attitudes and behaviors (mine included). As such, I presented my ideas and hopes for this project, still naïve, to David Barnard, JD, PhD, and Howard Degenholtz, PhD. Over the past three years, their persevering mentorship and support have not only helped develop this project from an initial spark to a full-fledged qualitative study, they have also assisted me in my own maturation as a student, a young researcher, and as an emerging adult. As such, their guidance will always remain a part of my memory and I can only hope to one day fulfill the same role in another student's education. I must also mention the contributions of William Klein, PhD to this project, as his expertise of young adult psychology and risk perception are invaluable to this paper.

I would like to thank Teresa Orkoskey, PharmD, whose assistance, not only as a 24-hour sounding board, but more importantly, as a qualitative rater, has been a pivotal element of this study. My thanks are also extended to Russell Davis, for his help in reviewing periodic drafts and for creating the illustration of the ideological model related to end-of-life decision making, found in Appendix H. Diane Lape's selfless assistance with focus group transcription also made this project possible to be completed by a single student concurrently taking classes. Additionally, I may never be able to fully express my gratitude to Dean G. Alec Stewart and Karen Billingsley of the University Honors College for allowing this project to successfully take flight, by faithfully providing me with the requisite funding.

This thesis is an extension of a study performed by myself, in collaboration with Drs. Barnard and Degenholtz. Data reported in this work will also appear in a future publication. Portions of this research were presented at the 29th annual meeting of the Society for Medical Decision Making, in Pittsburgh, PA, which took place in October 2007.

1.0 INTRODUCTION

Since the United States Congress passed the Patient Self-Determination Act in 1990 (hereinafter PSDA) (1), advance directives have ascended to the forefront of medical ethics, affording competent adults the opportunity to coordinate their medical care in advance of potential incapacitation. It is estimated that 20-30% of Americans possess such documents in the post-Schiavo era. (2) Accordingly, a mass of scholarship has been devoted to the exploration of people's preferences regarding advance care planning, the rates of advance directive completion, and the barriers impeding their prominence in society. (3-18) Large-scale initiatives to increase advance directive completion have been implemented, the most prominent of these having been the SUPPORT study of the 1990's, which took place in two VA hospital systems. (3) These studies have spanned across the borders of race, culture, socioeconomics, gender, and disease state, yet have typically used subject samples over the age of 40. As such, they have overlooked the fascinating sector of society just granted the authority to reign over their own medical care, those aged 18-30. The processes of psychosocial development and individuation of emerging adults¹ pose unique considerations regarding advance care planning that merit recognition and sensitivity from practitioners and policymakers alike. The purpose of our study was to address this significant gap in the decision making literature by focusing on young adults' knowledge

¹ Introduced as a distinct period in human development between the ages of 18 and 29, "emerging adulthood" has recently been pioneered by psychologist Jeffrey Jensen Arnett. (see *infra* note 34)

and attitudes regarding advance care planning. Our study additionally questions the appropriateness of legal provisions, which may fail to recognize the developmental trajectory of emerging adulthood, and presume a stronger self-identity than this cohort may actually possess.

2.0 BACKGROUND AND SIGNIFICANCE

The *causes célèbres* of Karen Ann Quinlan, Nancy Cruzan, and Theresa “Terri” Schiavo have all broadcast a common message of the risks of morbidity and mortality, regardless of age and current health status. Interestingly, a linear progression among these three women has arisen, emphasizing the need for the documentation of one’s treatment wishes. While in the case of Quinlan no prior mention of her wishes could be recalled (19), a key component of the Cruzan trial (20) was the testimony of a friend, which was initially deemed as insufficient proof to conclusively determine her general treatment preferences. Most recently, Terri Schiavo’s legacy has shown that an undocumented wish, when privately conveyed to an unofficial proxy, can be challenged, as if it had never been mentioned. (21) Their uniting theme of young age aside, a cursory judgment might bring one to exalt these cases as testaments of the utility of advance directives. However, just as an experimental drug’s safety and efficacy are examined to reveal potential discrepancies among various cohorts, prudence must also be used when suggesting widespread advance directive creation.

Introduced as somewhat of a reactionary social response to the need for medical autonomy in light of the Quinlan and Cruzan cases, the Patient Self-Determination Act mandates that all institutions receiving federal funding must explicitly offer patients the opportunity to create an advance directive. Given that the average age of a patient visiting an emergency department in 2003 was 71.1, younger patients have a lower likelihood of encountering the

PSDA in practice. (22) This disadvantage holds special significance for the emerging adult population for several reasons, which are highlighted below.

2.1.1 Increased risk-seeking behavior

Of the ten leading causes of death among 15-24 year olds, all are possible sources of decisional incapacitation. (23) Literature related to hazardous behavior shows an association between youth and risk taking, which decreases with age. (24-25) The urge to partake in such behavior has been noted to increase with the effects of peer influence, alcohol, and risky sexual behavior. (24-31) Additional studies suggest that young adults lack sound perceptions of risk, leaving them exposed to unrealistic views of morbidity and mortality. (31-33) During a time when overarching parental authority dissolves, emerging adulthood has been noted as a time for self-focused behaviors which aid in the search for and the acquisition of adult-defining characteristics. (34) To some extent, these behaviors have been defended as necessary for the successful development of identity and autonomy.

2.1.2 Lack of affectedness and perspective

Valuations of health state utility and satisfaction have been shown to be variable among those who have experience with illness (theirs or that of a contact's) and those in the general population. (35-36) If young age can possibly be associated with a decreased probability of exposure to disease or the death of a close contact, then such individuals would arguably have fewer opportunities presented to them for introspection on morbidity and mortality, relative to those with such experiences. Older adults who have survived the death of a loved one are

continually reminded of their own approaching mortality, whereas emerging adults' inexperience may serve to reinforce perceptions of invincibility. As such, the potential worth that an advance directive might have in one's life might be underestimated, assuming that (s)he is even aware of its existence.

2.1.3 Affective forecasting and its implications on advance medical decision making

The idea that several psychosocial biases impact decision making in situations where future happiness is at stake has long been established, and recently, work by Peter Ditto and others has shown that these factors may hold additional import in the realm of advance care planning. (37-39) Our tendency to exaggerate the negative impact of an event on one's future wellbeing, and to undervalue the ability of adaptation, are known as *focalism* (40) and *immune neglect* (41), respectively. Again, in those with limited life experience, the reasoning necessary to overcome these biases may be decreased or absent, therefore providing one with an extremely pessimistic view of illness. Coupled with medical misinformation, primarily from the media (42), distortion of one's perception of disease response and recovery is quite likely. Taken together, these factors may complicate the already difficult process of imagining one's preferences for a future incapacitated state. The "projection" of current feelings, while in a state of *cool* emotion for an unimaginable *hot*, high-tension state (the *projection bias*), also poses issues related to inexperience with illness. (43) Considerations of pain, burden, prognosis, and reasons for perseverance during sickness might slip past an unaffected individual, prompting them to construct views that are fueled by age-mediated risk ignorance.

Also of note is the application of the Socioemotional Selectivity Theory to end-of-life decision making. (44) The creation of goals and the urgency given to their completion is believed

to be related to one's perception of his/her time left to live. Split into present and future-oriented goals, those who believe that death is remote direct their energy to endeavors which will bear the most fruitful future outcomes. Oppositely, those whose deaths are imminent redirect their focus to attain immediate or short-term satisfaction, primarily emotional. While advance care planning can be thought to be performed by individuals in both situations, their decisions and the motivations underlying them are likely to differ. An unaffected young adult might choose to tailor his/her preferences on "big-picture" details, which may also be subject to the aforementioned inexperience bias. For example, one might abstractly and superficially ascribe low utility to a life with end-stage renal disease and as such, decide against dialysis in an advance directive. On the other hand, a person suffering from a terminal disease may look to micromanage the final details of his/her life, having considered the impact that the disease has had upon his/her life. To decide which timepoint in one's life is better for the creation of an advance directive is to implicitly create an inappropriate value judgment. However, it is salient to take these psychological mechanisms into account, and recognize their potential impact on decision making in such serious contexts.

2.1.4 Relative instability of interpersonal relationships

While the legitimacy of surrogate decision making has been extensively questioned (45-48), with a recent meta-analysis finding a 68% (95 CI, 63-72) rate of concordance between patient and proxy (45), others still contend that a Health Care Proxy defends a patient's autonomy better than a potentially inflexible Living Will. In conditions where unforeseen complications arise during illness, it is hoped that a surrogate would be well enough aware of the

patient's general thought schemata to construct an idea of what the patient himself would decide upon. This model of decision making has at its core a premise of bilaterally understood belief systems and even perhaps, an assumed prior discussion of specific subject matters, e.g. end-of-life care. Unfortunately, in a population where death anxiety may be a factor preventing such dialogue, young adults may not be well suited for a patient-proxy decision making dyad. During a time when identity exploration is of prime interest (along with a distancing from parents), the potential for unstable and fleeting associations arises. As emerging adults are looking to define themselves as distinct agents in society, experimentation with relationships, both romantic and non-romantic, becomes commonplace. (34) Consequently, the strength of such bonds may be hypothetically too weak to be relied upon for life and death decisions. As such, we must question whether young adults are suitable candidates to elect proxies or to act as proxies themselves, given the possibility of superficial and relatively temporary friendships and romantic relationships.

2.1.5 Study rationale

Emerging adults coming into a period of identity generation face a number of significant considerations, which may complicate the already taxing process of self-reflection necessary to construct wishes for future medical therapy. While a notable increase in potentially reckless behaviors present the need for proactive planning, risk ignorance may serve to cloud young adults' perception of any inherent utility of advance care planning methods. Their inexperience in both years, and in life events concerning morbidity and mortality additionally suggest that such individuals may form arbitrary and contemporaneous decisions, without a long-term focus

to their wishes. Lastly, the instability of interpersonal relationships during emerging adulthood suggests the absence of a solid foundation on which an effective patient-proxy rapport is built.

In an attempt to identify the salience of advance care planning in relation to emerging adults, we chose an almost exclusively qualitative design. As this population has never been specifically studied, we were interested in eliciting the widest possible variety of responses, without the restrictions inherent to quantitative methods. Semi-structured focus groups were conducted so as to create a free and comfortable environment for our subjects, allowing for some digression, which may reveal latent beliefs. It is not our intention to put forth conclusions regarding this age group; rather, we offer various perspectives of subjects in our convenience sample. As such, the statistics we report are descriptive and speak only to the composition of our focus groups.

3.0 MATERIALS AND METHODS

3.1.1 Subjects

Six focus group sessions were conducted in Pittsburgh, Pennsylvania between February and April 2007. A total of 56 subjects, aged 18-30 years, were recruited from advertisements in two campus newspapers and the online social networking site, www.facebook.com. Participants were assigned to sessions with respect to gender and age, to promote a diversity of possible gender-specific and experience-related opinions. Subjects were compensated with a \$20 honorarium for their participation.

3.1.2 Data collection

The focus group sessions began with a survey created by the investigators, which collected demographic characteristics and measured the degree to which participants were “affected” by end of life care decision making. (see Appendix A) Affectedness was defined as: a) having an illness which required continual medical monitoring, or hospitalization (“primary affectedness”), or b) knowing a close personal contact who had a similar life-threatening condition (chronic or acute), and/or the death of a close contact (“secondary affectedness”). The survey asked subjects to assess their baseline knowledge of advance directives in a yes/no/unsure checkbox format, and to provide a brief definition. The document included a section for subjects

to indicate prior advance care planning or end-of-life discussion (e.g., “I have spoken with my parent,” “I have spoken with my friend,” etc.) in a checkbox format. Subjects were asked to provide a written definition of advance directives and were then administered the administered the Hopkins Competency Assessment Test (HCAT) (49). The HCAT consists of a passage describing informed consent through end-of-life decision making a post-test questionnaire, used as a cognitive validation method. We used the version of the HCAT written at the eighth grade reading level.

After completing the written surveys, subjects were briefed on Persistent Vegetative State, Locked-In Syndrome, coma, Living Wills and Durable Powers of Attorney. Next, a group discussion was held using a semi-structured interview guide that led participants through three main topics:²

- Attitudes and preferences for various advance care planning methods;
- Preferred treatment options if decisionally incapacitated; and
- Characteristics and value structures of their ideal proxy.

Data were collected using audio recordings and detailed field notes. A laptop computer and a 40 gigabyte iPod (Apple, Cupertino, CA) outfitted with a microphone were on site at the group sessions to capture two separate audio feeds of the discussions. To ensure optimal recall, the moderator created memoranda immediately after the conclusion of the sessions. The audio files were converted to text files, with judicious removal of trivial speech.

This study received exempt approval from the University of Pittsburgh Institutional Review Board prior to subject recruitment.

² Additional topics discussed in the focus groups were not used in this analysis included: qualities of a meaningful and complete life, characteristics of good and bad death, and organ donation.

3.1.3 Data analysis

Transcripts of the focus group interviews were analyzed following grounded theory and using a hybrid inductive and deductive analysis style. An *a priori* master code list was created by the primary investigator, using multi-level codes, which referred to detailed descriptions of the themes in a compact label (e.g. “INF-MD” would reveal that the subject spoke of the influence of a physician, perhaps during a consultation regarding advance planning or in the event of a medical crisis). A list of select codes can be found in Appendix B.

Two reviewers (DK and TKO) independently analyzed the transcripts, in a three-step process. During the first reading, the reviewers superficially analyzed a transcript, making marginal notations of apparent themes. This was performed so as to promote an unbiased and thorough understanding of the interview content. The second step had the investigators critically read the transcript, refining their marginal notes into succinct codes. The final independent step was for the reviewers to apply the codes from the master list to the interviews, making revisions in the event of overlap between their own codes and the master set. Each of the subjects’ responses were read as a whole, and each sentence was also broken into its components so as to ensure complete extraction of ideas. Consensus meetings were held after each transcript was coded to ensure complete agreement on content interpretation, as a method of ensuring inter-rater reliability. Field notes taken by the moderator were consulted at the meetings and were reviewed for any insights which were not revealed within the transcripts.

Themes which arose from the transcripts were created into new codes and were retrospectively applied to previously analyzed data, while obsolete codes were either deleted or merged into other labels. We believe that our complex execution of iterative coding afforded us the goal of “thematic exhaustiveness.” Finally, face validity was assessed from public

presentation and discussion of the data in two separate colloquia - one composed of bioethics faculty and the other composed of undergraduate students in a thanatology course.

The demographic surveys and HCAT documents were analyzed by the same reviewers. Once again, consensus meetings were held to arbitrate any discrepancies in interpretation.

Qualitative analysis was performed using NVivo7 (QSR International, Doncaster, Australia). Emergent trends in beliefs and preferences between subjects were discovered via sequential and iterative compound code queries.

4.0 RESULTS

Focus group participants ranged in age from 18 to 30 years (mean = 21) (see Appendix C). Seventy-five percent were female, 70% were Caucasian, and 64% indicated a Christian religious affiliation. The average level of educational attainment was junior (3rd year) undergraduate status. All of our subjects were found to be cognitively sound, having scored 7 or higher on the HCAT test (mean \pm SD = 9.06 \pm 1.04). Forty-seven percent of the sample stated that they were planning to enter into a helping profession, e.g., medicine, mental health, social work, rehabilitative sciences, or public health. Eleven percent of the subjects disclosed significant personal medical experience, as defined by our aforementioned criteria. Sixty-four percent had been exposed to the serious illness and/or death of a close contact, where 32% of those were attributed to cancer. Sixty-one percent (n = 35) stated that they had performed some fashion of advance care planning, most frequently consisting of a discussion with their parents/guardians (26%, n = 15). (see Appendix D)

Fifty-six percent of our subjects had correct baseline knowledge of advance directives, listing at least two of the five components of a proper definition. (see Appendix E) Subjects most frequently understood that advance directives act as a repository of treatment preferences for when patients themselves cannot properly exercise individual will. Subjects were less likely to know that advance directives are only created when one is of sound mind, and that they allow for the designation of a proxy decision-maker. Of the 28 subjects who correctly described advance

directives, 25% (n = 7) were initially unsure of their own knowledge. Additionally, 22% (n = 11) of the subjects incorrectly defined advance directives, despite believing that they knew the proper definition. Sixteen percent (n = 8) of the subjects who were not confident in their baseline knowledge provided incorrect responses.

Several misconceptions of advance directives and their functions were evident in the subjects' responses. (see Appendix F) Confusion with other legal documents, such as Last Wills and Testaments, and traditional (financial) Powers of Attorney, were the most common type, while other subjects believed advance directives to be funeral planning documents. Lastly, one subject believed that advance directives were only valid while holders of such documents were hospital inpatients.

4.1 QUALITATIVE FINDINGS

Our content analysis revealed seven potential variables bearing on the likelihood of one's performing advance care planning, which are depicted in Appendix G. The observations distinct to this study can be discovered in Section 4.1.2: Psychosocial Influences on Decision Making.

4.1.1 Attitudes regarding advance directives

The majority of participants responded positively regarding advance directives. Seventy-three percent (n = 41) of our subjects stated that they would be comfortable creating such a document within six months of the focus group session, some even immediately. The preference most frequently voiced by subjects was the creation of both a Living Will and a Durable Power

of Attorney, in the event of unforeseen complications requiring additional decision-making. Of the subjects who supported the creation of advance directives, many noted their utility in the retention of medical autonomy and their ability to preclude any possible subjective decisions regarding their treatment made by others. One subject exposed a viewpoint that was common within our interviews when she implicated advance directives in defense of her legally-sanctioned adult liberties:

Subject: I definitely feel very comfortable [creating an advance directive] because I think I am a real person. I am considered legal in the US to drink... And, I feel most comfortable making this decision for myself, rather than having someone like say, my parents making this decision for me, because I mean, no one knows you better than you know yourself. So despite how uncertain you are, or unwilling you might be to make these hard decisions, it's far better than having someone else make these decisions for you, that you don't agree with.

Subject: Yeah, I think that my sisters and I have the same kind of values. There has been a situation before...my little sister, she was going to get a treatment and my parents didn't want it at all. But, she went through with what she wanted to do and it turned out fine. But, our parents sort of have a little conflict of interest in our lives.

Subjects who were uncomfortable or uninterested in drafting an advance directive at the time of the interview generally provided very animated and sharp answers. The majority of these responses reflected insecurity in opinions, a refusal to acknowledge personal vulnerability, or a lack of confidence in medical knowledge and in their own maturity. One participant voiced a negative perception of advance care planning, believing that it only perpetuates medicolegal confusion and is a product of selfish motivations. Apart from this maverick subject, the

remainder of the participants believed that advance directives possess inherent value, even if they did not find them personally appropriate.

Subject: I would absolutely not make [an advance directive] right now. I lack the legal knowledge, I lack the medical knowledge, and general life knowledge right now. I don't trust a lot of the decisions I make now, so I definitely would not make a decision like that.

4.1.2 Psychosocial influences on decision making

4.1.2.1 Physical and emotional burden

A number of factors emerged that influenced participants' likelihood of performing advance care planning at their current age. Most frequently were fears related to the mismanagement of their care, by both family members and medical staff. Some used this argument to support the salience of advance directives due to value differences between them and their families, while others preferred to ascribe the duty of decision-making on their parents. The imposition of a burden upon survivors either as proxies or as caretakers, was expressed from opposing points of view.

Subject: I think that at this point in my life, I don't feel like I have a responsibility to write that down because if [incapacitation] would happen to me, it wouldn't be a particular burden on anyone but my parents and my fiancé, and maybe they could work it out together? But especially with children, I think you definitely have the responsibility to write everything down, so that they don't get caught in the middle of it.

Subject: If I was in a PVS, and if I was in any way coherent [sic], I would want to stay alive. I think even if I was a burden on my family and couldn't take care of myself, they'd keep me alive, even if they had to care for me.

4.1.2.2 Social independence and individuation

Subjects referenced their perceptions of social independence and individuation from the nuclear family as markers of their readiness and willingness to perform any advance care planning. Momentous life events, such as graduation from college, the beginning of a career, long-term partnership, and parenthood, were identified as time-points when subjects felt end-of-life decision-making to be paramount. Additionally, many respondents mentioned that the feeling of being an individual unit in society upon which no one depends, was both a motivator and a barrier to action. In feeling socially isolated, subjects recognized the need of an advance directive to shield themselves from parental involvement, or that the lack of dependents obviates the need for such proactive decision making.

Subject: I think if I had to, I would make one right now. But, I probably won't, because I don't really think that I have a need to, as horrible as that sounds....Nobody really thinks that their life depends on me, so I don't have that much need for it.

4.1.2.3 *The Achilles Complex and The Reality Principle*

Discussion centered on the utility and purpose of advance directives uncovered many subjects' beliefs in age-mediated invincibility. Subjects voiced anxiety, sadness, and disgust when speaking of their susceptibility to incapacitation or death at their current age. Acting as a potential seed for further introspection was the mass homicide at Virginia Tech University (16 April 2007), which occurred prior to the final three focus group sessions, and was mentioned by multiple subjects. Additionally, participants were especially disturbed whenever the Schiavo incident was referenced, which occurred in every session.

We identified two phenomena from subjects' responses regarding risk perception and death anxiety. The first, which we have named the *Achilles Complex*, addresses a notion of decreased or absent susceptibility, due to youth and vitality. Several subjects also stated that a lack of personal experience with serious illness (primary and/or secondary affectedness) impeded their ability to realize any risks of harm. For this, we have borrowed the title, *Reality Principle*, from Freudian psychoanalytic theory. It is interesting to note the feedback dynamic between these two concepts. For example, one subject who mentioned that he had never experienced the death of a close contact, went on to say that because of this and his own luck with good health, had admittedly become more risk ignorant than his peers:

Subject: I definitely could not plan it now. I just can't plan for my own death now, I dunno, I just, I'm too young. I'm just too healthy now. I guess what it would take for me to do it would be a brush with my own death, and not even one of a family member, like a heart attack or a bad car crash...I guess I would just really have to feel that my death were close.

Some of these same subjects also viewed advance directives as harbingers of morbidity and mortality, claiming that they refused to plan their own deaths. These beliefs are consistent with a prior study's finding that advance care planning is commonly thought to be reserved only for the very ill or the very old. (50) While those who held such beliefs were generally able to articulate them, others displayed absolute reticence when probed for additional details.

Moderator: Let's say that I were to give you the opportunity right now to create an Advance Directive, with do-it-yourself kits. Would you take me up on it?

Subject: Hell no. At this point in my life, I don't want to be thinking about death.

Subject: Well, if it were now, I wouldn't do anything, because I don't want to plan my own death. I mean, it might be smart, it might be good for other people, but I can't do that....

4.1.3 Preferred proxy characteristics and behaviors

Subjects who chose to designate surrogates in the hypothetical incapacitation scenario generally provided similar justifications for their selections. A tabulation of preferred surrogates can be discovered in Appendix G, which shows that 66% of our sample population was interested in electing a proxy. Most subjects' first-line answers were that the chosen proxy "knows me the best," and that that they had absolute trust in the proxy's inherent ability to make "good decisions" for the provision of their care. When probed for clarification of how they believed that their proxy would form his or her decision, subjects primarily believed that the

proxy would employ a “best interest” heuristic. Subjects also stated that their proxies shared similar values and ethical standpoints, making them more comfortable in the hope of truly reflective surrogate decision making. Those who feared parental subjectivity (e.g. excessive use of life-sustaining treatments) frequently chose siblings, partners, and friends, citing ideological proximity. However, other subjects welcomed their proxy’s potential subjectivity, and some even afforded their proxies *carte blanche* authority:

Subject: I’ve been sitting here going back and forth. I know kind of an idea of what I want and that my fiancé has a general idea of what I’d want and if he would honor that or prolong that. I’m kind of leaning toward that he would prolong [my life] longer than I would wish. But, that doesn’t really bother me in any way. If they’re his wishes, then they’re my wishes, too.

5.0 DISCUSSION

This study is the first to our knowledge to specifically take interest in the preferences that emerging adults have for advance care planning. Our findings suggest that the variability in several key psychosocial and developmental factors in this population merits attention from clinicians and legislators alike.

Regardless of their views on advance care planning, subjects consistently spoke of concepts related to individuation. Defined by Erich Fromm as, “the growing process of the emergence of the individual from his original ties,” individuation implies more than the privileges and responsibilities that are bestowed at the twenty-first birthday. (51) While we may colloquially associate age with increasing independence, results from this study reveal discrepancies that contradict this notion’s universality. Subjects frequently cited various life events (most in the future) as heralds of responsibility, indicating that individuation is not a fixed timepoint. As expected, consensus was not evident regarding the specific ages of onset and completion of the individuation process. For some, the insistence to delay autonomous medical decision making was also related to a reliance on parental authority and judgment, well beyond the ages of 18 and 21. Statutes which default surrogacy to parents or guardians may complement such patients’ wishes, yet potentially present serious impositions to others.

Many subjects described advance care planning as an affirmation of independence, just as any other movement of detachment from the vestiges of childhood. Similar to positive

justifications used by others, our subjects appreciated the reassurance that autonomous healthcare planning affords them. Other subjects, however, voiced fear and disdain toward the perceived rigidity of such legal documentation. Perhaps fueled by the misconception that a Living Will is exclusively a set of negative proscriptions in the withholding of treatment, many spoke of such decision making as a legal suicide plan. Despite the ten-minute introductions at our interviews which carefully described advance care planning, a minority of participants retained factual errors throughout the sessions. It is unclear whether these reasons of distaste for end-of-life decision making are borne from cultural or religious traditions, or if they are products of misinformation.

Additional medicolegal misconceptions peppered our interviews, with confusion related to advance directives and the disease states which merit the activation of such documentation.

Subject: If I was in a PVS, and if I was in any way coherent [sic], I would want to stay alive.

While we report baseline knowledge of advance directives within our subject sample at 56%, it is crucial to study the composition of all of the responses elicited. Sixty-two percent of our subjects indeed understood a Living Will's main function of stating a patient's treatment preferences, yet only 10% realized that an advance directive also provides for proxy election. This discrepancy calls into question the importance rank-order of the various functions of advance directives, suggesting that more weight be placed on a colloquial understanding of an advance directive's functional definition, rather than an exacting statutory description. These findings dovetail with a study of hospital inpatients wherein 18% responded that they did not know what a Living Will was, while 51% said that they "had heard of it, but did not know

enough about it.” (52) Additionally, 43% of their sample incorrectly believed that an advance directive can prevent cardiopulmonary resuscitation in non-terminal states. Stark deficiencies in a holistic comprehension of advance care planning beckon educational promotion to all age groups. As one subject poignantly noted, young adults especially, are in need of a “wake-up call,” and advocated interventions specific to college students:

Subject: It's something I didn't really think about, even with family members in the hospital. It's something the older relatives talk about, but not with the younger ones. But, even now with something like being in college, why can't that be part of your freshman courses? It's something that definitely can be taught in college courses.

The proviso of having a “sound mind,” on which the validity of many state advance directive documents hinge, at first glance refers to the cognitive health of the testator. We challenge that this concept falls short of including within it, the ideas of identity and individuation. Contemporary legal constructs not only require persons to have definite wishes regarding medical care, but also more importantly, to imagine hypothetical scenarios of illness. While these two stipulations are key in producing an accurately reflective declaration, they unfortunately may discriminate against young adults. Language in advance directive forms expect that one is able to pit themselves at the edge of life, by including statements such as the following, taken from the popular *Five Wishes* form: “If my doctor and another health care professional both decide that I have permanent and severe brain damage, (for example, I can open my eyes, but I cannot speak or understand) and I am not expected to get better, and life-support treatment would only delay the moment of my death...” (53) While this task may be extremely challenging for anyone to complete, it may be inappropriate to expect this of young

adults. Relative to their elders, it is far likelier that they have had fewer experiences with severe illness (personal or witnessed), if any, which may impede their ability to invoke the requisite imagery upon which life-sustaining treatment preferences are based.

Decisionally impotent young adult patients propose a very unique ethical dilemma, rife with potential legal pitfalls. If in the event of incapacitation, proxy authority is granted to a patient's parent, we must hope for the concordance of this agent's actions to the patient's values. At an age when "growing aloneness" (51) may fashion a divide between youth and adult, we must use caution when deciding whose voice can best replace a patient's. The surge of nontraditional relationships ignored by the law only serves to deepen this issue, by challenging the idea that a spouse will eventually replace a parent as a default surrogate. Youths are delaying marriage, and extending the length of courtship and engagement, in pursuit of education, financial security, or personal fulfillment, as indicated by an increase in the median age at first marriage since 1970. (54) Additionally, public homosexual partnerships, which are similarly increasing in prevalence, leave these individuals at risk of losing the reassurance of a partner's voice in their medical care.

5.1.1 Study limitations

This study has several limitations. Firstly, our subjects were all recruited from university campuses, possibly injecting our results with an educational bias. A previous study has shown that advance directive completion rates are related to higher education. (6) Secondly, we question to some degree, the validity of the responses elicited, due to two phenomena. The first has been noted by Kreuger, wherein subjects spontaneously mimic the perceivably salient or distinguishing comments of a previous respondent. (55) Additionally, we are curious of the

fidelity of the responses due to the serious thematic nature of our discussions. It is perhaps imaginable that when caught off-guard by such deeply probing and existential topics, one might provide a superficial or even invalid response – a phenomenon which could be evident in any study on end-of-life care. However, due to the rigorous and multi-faceted methods used, we ultimately have faith in our conclusions. Additionally, our cohort was primarily Caucasian and female, most likely preventing the generalizability of our findings.

5.1.2 Implications for research

While our study cannot make any population-wide claims due to our research design, we do support the idea that further investigation of this age group's knowledge and preferences for end-of-life decision making should be performed. We have identified several phenomena, such as the *Achilles Complex* and the *Reality Principle*, which should be validated in a thorough quantitative format. Additionally, four significant themes emerged from our interview data, which are mentioned on page 15: (1) insecurity in opinions, both medical and moral; (2) risk ignorance; (3) lack of confidence in medical knowledge; and (4), lack of confidence in one's own maturity.

Our study has set the stage for extensive research efforts to investigate these findings in larger sample sizes, and to offer more conclusive data for policy evaluation and adjustment, if deemed appropriate. Specifically, we believe that the risk ignorance evident in our subjects' responses merits further study. While previous studies have looked at young adults' risk perceptions related to certain behaviors and disease states (24-33), it may be advantageous to examine risk perception specifically related to end-of-life decision making. These findings may vary in persons with different levels of primary and secondary affect (e.g. personal illness, death

of a close contact), and as such, should be distinctly examined. Secondly, it is conceivable that the lack of confidence in one's medical knowledge and the insecurity in one's personal preferences that we noted may not be age-specific, and thus should be studied cross-sectionally. While numerous significant life events typically occur during young adulthood, all periods of adulthood are subject to changes and tumult, which may subsequently affect views on medical care. Lastly, we suggest a study to observe the level of concordance between hypothetical young adult patients and their parents, regarding life-sustaining treatment. As parents are legally-assigned default surrogates, results from such a study may reveal information useful in evaluating the appropriateness of such proxy hierarchies for young adult patients.

5.1.3 Implications for policy

Despite studies having shown that the stability of preferences for life-sustaining treatment varies considerably over short periods of time (56-57), we believe that all competent adults should be afforded the opportunity to secure their medical autonomy. The great flux and instability of emerging adulthood may make this time period seem inappropriate for decision making, however it is for this exact reason that advance care planning is imperative. As others have previously proposed, we support the creation of advance directives with "expiration dates," requiring periodic reappraisal. (37) This forces young adults to revisit the document and in light of possible developments or shifts in personality, to readjust their wishes accordingly. Even if such an advance directive is only reflective for 21 months, it is important to keep in mind that those 21 months were spoken of with the patient's honest and valid beliefs at heart. Any incidents occurring during that time period would be resolved with the most contemporaneous model of the patient's ideals. State and federal policies regarding advance care planning must be

careful not to exclude this population from the discourse on end-of-life decision making on the basis of their age. Young adults, just as any other cohort, should be afforded the opportunity to administrate their medical care, using evidence-based and age-appropriate methods.

5.1.4 Implications for clinical practice

Regarding clinical practice, it is quite plausible that physicians might be uneasy to speak of end-of-life issues with emerging adult patients. Nevertheless, a survey of patients' harmful behaviors during intake may serve to be an ideal time for such discussions. Lastly, we recommend that educational interventions concerning advance care planning be made in high school and college settings, as these venues may provide public health professionals with the easiest access to this risk-taking population.

6.0 CONCLUSION

Our qualitative study presents novel data regarding young adults and end-of-life decision making, which suggest that established statutory frameworks for advance care planning may be inapposite to this age group. Blind to the unique developmental nuances of emerging adulthood, traditional advance directives presuppose life-defining experiences and force life review and social network appraisal, which may be affected by the amount of time lived after adult individuation. We report that the subjects in our study displayed limited functional knowledge of advance directives and harbored misconceptions concerning such documents' roles and applications in therapy. Additionally, a high level of variability was found among subjects regarding their preferences for surrogate decision making and the level of authority to be extended to such agents. We recommend further validation of our findings in a more rigorous manner, and anticipate state and federal policy review in light of these conclusions.

APPENDIX A

**DEMOGRAPHIC INTAKE AND ADVANCE DIRECTIVE KNOWLEDGE
QUESTIONNAIRE**

End-of-Life Decision-making Focus Group – Demographics Questionnaire

Please complete the following survey, responding to the best of your knowledge.

Name (first only): _____ ID: _____

Age: _____ Year (#) in school: _____ Sex: M F

Religion: Christian Jewish Muslim

Hindu Other _____ Atheist

How important would you say that your religious faith is in your life?

Not important Moderately Important Very Important

1 2 3 4 5

Ethnicity (optional): Caucasian African-American Asian/Pacific-Islander
 Hispanic Middle Eastern Other _____

Have you ever had a serious illness that has required: a) hospitalization b) continued medical monitoring and/or places you at risk for death and/or serious illness?

Yes: (Please list illness: _____) No

Has anyone in close contact to you (family, friends, etc.) experienced the conditions listed in the previous question and/or death? Please list closest person whom this applies to, if yes.

Yes: (Please list illness: _____) No

Please define what your area(s) of study is/are, and what is your intended terminal degree to be (i.e. BS, BA, MA, PhD, JD, MD, etc.).

Intended area of study: _____

Intended terminal degree: _____

Do you know what an Advance Directive is?

- Yes No Unsure

If *yes* or *unsure*, please define an Advance Directive below in one or two sentences.

Have you ever performed any end-of-life advance care planning (please check all applicable options)?

- Advance Directive (aka "Living Will")
- Durable Power of Attorney
- Spoken with parent
- Spoken with physician
- Spoken with another (Relationship to you: _____)
- Other (describe: _____)
- None

APPENDIX B

EXAMPLE OF CODES USED IN DATA ANALYSIS

CONSIDERATIONS

CON-FAM	Family's wishes; familial consultation “...as long as there are no strong objections from the family...”
CON-QOL	Quality of life
CON-RES	Limited resources; monetary cost
CON-REG	Regard for others; burden on others
CON-PAIN	Pain
CON-FUT	Medical futility (no recovery) “...if there's no resemblance of how they were...”
CON-DIG	Death with dignity

MOTIVATIONS

MOT-AUTH	Authority; control; complete decision-making power “I know it creates a lot of conflict, but if I had the authority...”
MOT-SD	Self-determination

	“I make the decision regarding my care.”
MOT-HOP	Hope
	“I’d say wait a little...there’s always the glimmer of hope.”
MOT-RELUCT	Reluctance to make a decision
MOT-UNW	Unwilling to make any decisions; complete reluctance
	“I mean, if I could, I might just sign him off to someone else so that it wouldn’t weigh on my soul so much.”
MOT-REAL	<i>Reality Principle</i> ; Event must motivate subject to act
MOT-SELF	One’s own feelings or grief as a surrogate

PROXY PREFERENCES/EXPECTATIONS

PROXY-PRIOR	Subject’s hypothetical and practical desire to discuss treatment preferences with proxy
PROXY-SIMVAL	Proxy has similar values
PROXY-KNOWPT	Proxy knows pt best
PROXY-OBJ	Proxy is expected to act objectively
PROXY-TRUST	Subject trusts intended proxy’s inherent ability to make “good” or “right” decisions
PROXY-SUBJ	Subject appreciates proxy’s subjectivity in decision making

APPENDIX C

SUBJECT DEMOGRAPHICS

Characteristic	n (%)
Sex	
Male	42 (75)
Female	14 (25)
Mean age (range)	21 (18-30)
Religion	
Christian	36 (64.3)
Atheist	4 (7.1)
Jewish	3 (5.4)
Other	13 (23.2)
Ethnicity	
White, non-Hispanic	39 (69.6)
African American	8 (14.3)
Asian and Pacific Islander	8 (14.3)
Hispanic	1 (1.8)
Mean years of education	15 (undergraduate junior)
Helping profession	26 (46.4)
Personal illness	6 (10.7)
Close contact illness and/or death	36 (64.3)
Cancer-attributed	18 (32.1)

APPENDIX D

PRIOR END-OF-LIFE DECISION MAKING

Method	n (%)
Discussion with parent	15 (26.3)
Discussion with non-spouse partner	5 (8.8)
Discussion with friend	2 (3.5)
Discussion with physician	1 (1.8)
Discussion with other relative	1 (1.8)
Advance directive creation	1 (1.8)
Health care proxy designation	1 (1.8)
Total Prior Advance Care Planning	35 (61.4)

APPENDIX E

KNOWLEDGE OF ADVANCE DIRECTIVES

Components of definition	n (%)
Formal, legal document	19 (38)
Activated upon uncommunicativeness	24 (48)
States treatment preferences	31 (62)
Allows for proxy designation	5 (10)
Drafted while cognitively intact	1 (2)
Total Correct Definitions	28 (56)
Correct True Definitions (“Yes” → Correct)	21 (75)
“Unsure” → Correct Definitions	7 (25)
Total Incorrect Definitions	19 (38)
False True Definitions (“Yes” → Incorrect)	11 (22)
“Unsure” → Incorrect Definitions	8 (16)

APPENDIX F

MISCONCEPTIONS REGARDING ADVANCE DIRECTIVES

Misconceptions	n (%)
Last Will and Testament	16 (32)
Traditional Power of Attorney	2 (4)
Funeral planning document	2 (4)
Only active while inpatient	1 (2)
Total Misconceptions	21 (42)

APPENDIX G

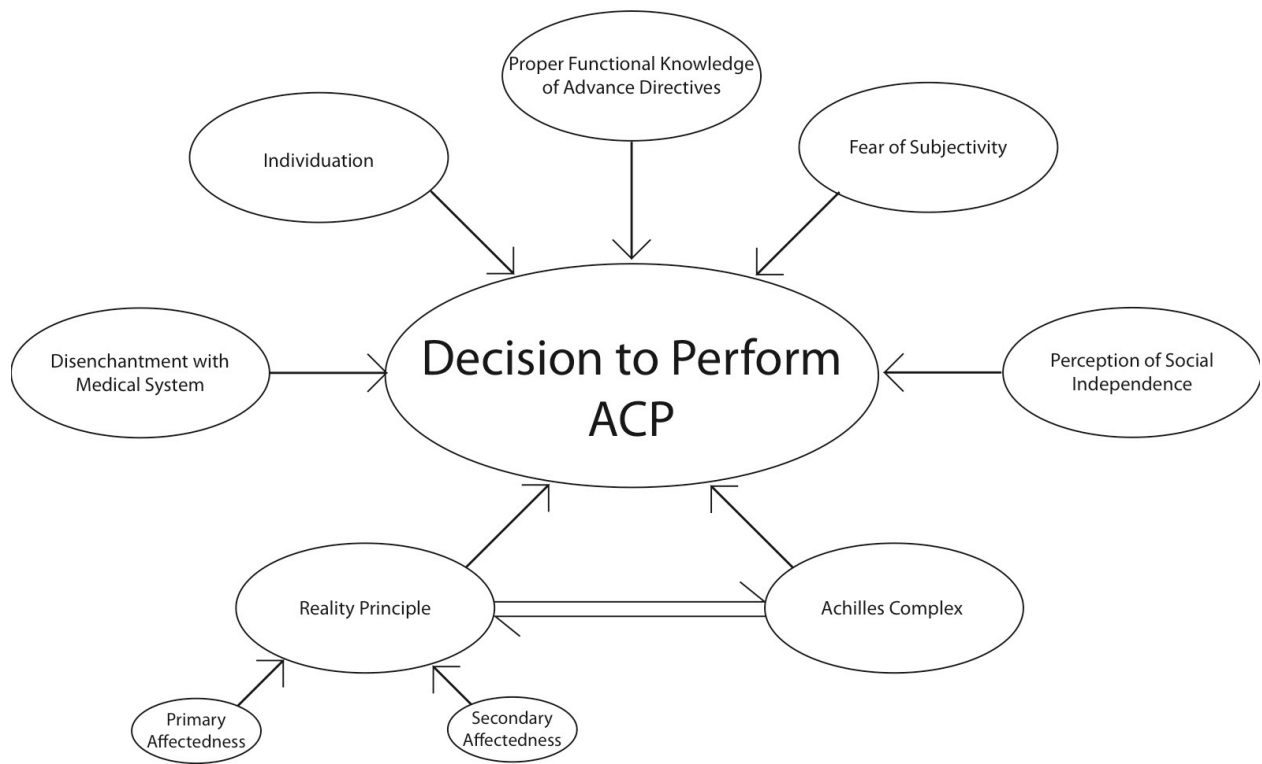
PREFERENCES FOR HEALTH CARE PROXIES

Preferred Proxy	n
Mother	10
Parents, non-specific	9
Sibling	8
Father	5
Non-married partner (fiancé, domestic partner, boyfriend)	3
Friend	1
Other relative	1
Subjects interested in proxy election	37 (66%)

Note: Subjects were asked to disclose their preferences, assuming incapacitation at the time of the interview, not in the future. As such, responses indicating an intended transition from parental to spousal/partner authority would have been recorded as the former.

APPENDIX H

MODEL OF POTENTIAL FACTORS RELATED TO EMERGING ADULTS' PROBABILITY TO PERFORM ADVANCE CARE PLANNING



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